Creating a Dementia Capable Health Care Home

An Evaluation of an Essentia Health Initiative

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Background

In 2013, Essentia Health received a Community Service/Services Development grant (now referred to as Live Well grants) from the Minnesota Department of Human Services to design and implement new strategies for a dementia capable health care home model. In response to the dramatic growth in the population of older adults in Minnesota and increasing rates of dementia, Essentia Health recognized the importance of a standardized and centralized approach to early dementia diagnosis. With dementia as an organizing principle of care, protocols were embedded in electronic health records and served to guide Essentia staff through new standards for diagnosis, care, and supports for people with Alzheimer's disease, dementia and Mild Cognitive Impairment. The guiding principles for this project included:

- Improving all aspects of dementia care, including diagnosis, support, and management of the disease along with other comorbid conditions
- Improving outcomes for patients and families, through a centralized approach to access to care and timely delivery of services

Essentia Health contracted with Wilder Research to conduct a formal qualitative evaluation of the Dementia Capable Health Care Home Project. The original goals of the evaluation were to:

- Assess the effectiveness of health care home and partner community organizations in implementing dementia service protocols and integrating them into home- and community-based service systems
- Assess the impact of protocols on individuals and family members
- Examine the costs and benefits associated with changes to dementia care protocols

Program model

Essentia staff created a process work flow for each step of patient engagement with health care providers, care coordinators, and community support providers. The work flow protocol was embedded in the EPIC medical records, and prompted medical practitioners to implement patient care best practices and protocols, including labs and other tests, referrals, treatment options and instructions for patients and family members.

The work flow process, or dementia SmartSet[1], was first implemented at both clinics, beginning in January 2014. MiniCog[2] testing was completed for individuals aged 65 and older at their Annual Wellness Visit or other primary care physician office visit. Individuals who scored less than 4 on the MiniCog were scheduled for MoCA©[3] testing at a subsequent visit, but scheduled as soon as possible, and preferably within 14 days. Individuals who failed the MoCA© were scheduled for a complete dementia work-up[4], based on the decision support guidelines in the EPIC SmartSet. Following a diagnosis of Alzheimer's disease, Mild Cognitive Impairment (MCI)[5], or related dementia, care coordinators at Essentia Health developed care plans, and managed the follow-up care and referrals for patients and their families, according to established care coordination protocols.

Individuals and their care partners who signed a Release of Information form were referred to community partners for additional services and supports. Four community agencies partnered with Essentia Health: Alzheimer's Association, Arrowhead Area Agency on Aging, Northwoods Partners, and Age Well Arrowhead.

Referrals were specifically coded for education and support for the patient, family, or other care partners; respite, assistance for arranging for non-health related services, assistance with managing or paying for medications, questions about Medicare or other health insurance, transportation, assistance with managing finances or service payments, safety concerns or home modifications, and advanced health care directives. Community partners reported back to physicians to inform them of the status of the referrals, including which services had been offered, and which had been accepted.

A detailed work flow process map is located in the Appendix.

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[1] The dementia SmartSet was embedded in EPIC health records, with prompts for the medical practitioner

[2] MiniCog is a brief 3-part test that is used to screen for cognitive impairment and identify the need for further evaluation.

[3] The Montreal Cognitive Assessment (MoCA)© is a 30-point test used to assess mild cognitive impairment. It assesses visuospatial and executive function, naming, memory recall, sustained attention, language, abstraction, and orientation to time and place.

[4] Includes lab tests, imaging, neuropsychology testing

[5] For purposes of analysis for this study, Mild Cognitive Impairment and Cognitive Impairment (subjective memory impairment assessment) are combined as one diagnosis.

Program timeline

Following extensive planning completed from October to December 2013, patient interventions were implemented beginning in January 2014 at two Essentia Health clinics—West Duluth and Ely. Monthly meetings to monitor and track progress on the implementation continued through July 2015.

Figure 1 shows a detailed timeline of activities[6].

1. Program activities timeline

Dates	Program activities
October 2013 to December 2013	Implementation planning finalized Team members identified at two sites—West Duluth and Ely EPIC SmartSet finalized Pilot test of process Outreach, education, training for implementation
January 2014 to July 2015	SmartSet implemented at two sites Monthly team meetings to monitor and track progress
May 2014 to December 2014	Monthly meetings of stakeholders to develop work flow process
November 2015	Care Providers of MN conference presentation
July 2015	End of official project activities

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[6] Timeline of activities provided by Essentia Health staff.

Methodology

Wilder Research completed three main tasks to assess the successes and challenges of implementation efforts encountered at the two Essentia sites, as well as the impact of dementia care protocols on individuals and family members.

- Analysis of summary data for patient outcomes at the two clinics, provided in aggregate form by Essentia Health staff
- In-depth telephone interviews with 21 staff and community partners, including:
  - 9 clinical and administrative staff at the West Duluth and Ely clinics
  - 2 Essentia Health research and technical staff
  - 5 medical and service management staff at Essentia Health headquarters
  - 6 project partners at the Alzheimer's Association, Arrowhead Area Agency on Aging, Northwoods Partners, and Age Well Arrowhead

The methodology and questions for the telephone interviews with staff and community partners were submitted and received Essentia Health IRB approval before the project commenced. Essentia lead staff provided Wilder Research with a list of staff and community partners' names and contact information for interviews. Wilder Research made initial contact with key informants by email to introduce them to the study and invite them to participate. For those who could not be reached by email, a follow-up a phone call was made. Wilder Research scheduled appointments for phone interviews, at the convenience of Essentia staff and community partners. Key informants had the option to decline participation in the study at any time, and were informed that their comments would remain confidential.

- Telephone interviews with 2 family caregivers who were assessed and followed at one clinic site

HIPAA rules, IRB requirements, and time limits on data collection activities prevented researchers from acquiring patient and caregiver contact information from Essentia records for telephone interviews with a greater number of family caregivers. Wilder Research worked directly with community partners to recruit families who would be willing to participate in a phone conversation to share observations about their participation in this project, including referrals to community partners. Recruiting family caregivers who fit the eligibility criteria and who had time to be interviewed proved difficult. Eligibility criteria included:

- Screening by Essentia Health clinic in Ely or West Duluth and referral for cognitive assessment
- Assessment indicating some degree of cognitive impairment
- Referral to one or more community-based service providers (Alzheimer's Association, AgeWell, or Northwoods Partners)

Participation was voluntary. Family members were reassured that participation would not affect the services they were receiving, and that all information gathered would be treated as confidential and private. Family members who participated in the phone conversation were offered a $50 gift card in the mail following the call to thank them for their time and contribution.

Findings

Patient outcomes

Plans to complete analysis of patient outcomes were altered following the legislature's decision to invoke funding rules in August, 2015. Data collection activity that produced evaluable outcomes ended July 31, 2015. Due to HIPAA protections and IRB requirements, Essentia staff provided Wilder Research with summary tables of aggregated data extracted from electronic health records, including:

- Number of patients with a dementia diagnoses
- Length of time between screening exam and final diagnosis
- Types and numbers of patient contacts with primary and specialty care
- Types and numbers of referrals to community partners for support services
- Total cost of care for individuals with dementia

Information on individual patient outcomes by diagnosis or follow-up care received is not included in this report.

Results

During the study period, 195 individuals had health care appointments that included cognitive screening (MiniCog and/or MoCA©, or MMSE[7]). Of these, 174 individuals received MiniCog and/or MoCA© testing, including 32 who had both tests, consistent with the implementation protocol. In all, sixty-six individuals received a diagnosis of Alzheimer's disease, MCI, or related dementia. They were referred for further diagnostic testing, including laboratory tests, imaging, neuropsychology testing, as well as neurology or psychiatry for follow-up care. Twenty-one individuals agreed to referrals to community partners. Figure 2 demonstrates the work flow implementation and numbers of individuals who received care at each stage.

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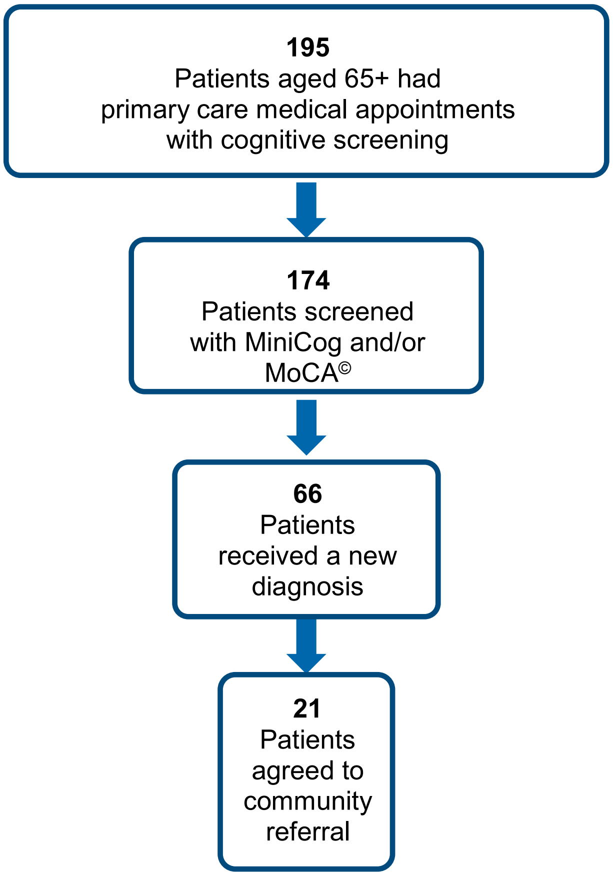
[7] The mini–mental state examination (MMSE) is a 30-point test that is used to measure cognitive impairment.

2. Work flow implementation



Note: 129 Patients had no new diagnosis of dementia

Diagnosis by clinic site

The percentage of new diagnoses (including Alzheimer's disease, dementia, and MCI) was 34 percent overall, including 25 percent at Ely and 40 percent at West Duluth. Overall, 43 percent of the patients were screened at Ely and 57 percent were screened at West Duluth. Figure 3 presents these numbers by site.

3. Diagnosis status by site

	Ely		West Duluth		Total	
	Number	**Percent**	**Number**	**Percent**	**Number**	**Percent**
New Diagnosis	21	25%	45[8]	40%	66	34%
Total Screened	83	43%	112	57%	195[9]	100%

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[8] Two patients received a diagnosis of "non-dementia related cognitive issues."
[9] Twenty-one patients received MMSE screening only.

Time between testing and diagnosis

A key objective of the program was to expedite the time between test and diagnosis, with a goal of 14 days. This portion of the data collection documented the number of days, in order to establish typical time ranges[10]. Figure 4 presents the range of days from test to diagnosis for individuals who received both MiniCog and MoCA© tests. With an average of 18 days and a median of 14 days from test to diagnosis overall, the range of days varied by diagnosis. Four individuals with a diagnosis of Alzheimer's disease had the shortest range with just fourteen days; 16 with MCI had a range of 38 days; 9 with a dementia diagnosis had the widest range with 57 days. Program staff indicated that the time span varied by individual, based on circumstances such as the existence of comorbid conditions and the need for additional medical interventions, family schedules, and the degree of urgency experienced by the individuals.

4. Days from test to diagnosis for patients who received both MiniCog and MoCA© tests

Diagnosis	Number of patients	Range of days from test to diagnosis	Average days from test to diagnosis	Median days from test to diagnosis
Alzheimer's disease	4	12-26	20	21
Dementia	9	0-57	17	14
Mild Cognitive Impairment (MCI)	16	4-42	17	13
Total	29	0-57	18	14

Patient contacts with primary and specialty care

Data were also collected about the types and frequency of patient and family encounters or contacts with clinic staff that occurred at 90 day and six month intervals before and 90 day and six month intervals after diagnosis. Types of encounters included telephone calls with clinic staff, email correspondence with clinic staff, clinic outpatient visits, Emergency Room visits, and hospitalizations.

The data show that phone contacts and email correspondence with clinic staff increased within the 90 day interval, but decreased slightly or remained the same within the 6 month interval.

While the aggregated data available to evaluators limited the scope of this analysis, clinic staff report that the increase in phone and email contacts at the 90 day interval may indicate improved follow-up through health care home management practices. Further study could demonstrate a more direct relationship for this outcome.

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[10] Data collection was not designed to connect the time range to individual level diagnoses or health outcomes.

Figure 5 presents the number of contacts or encounters 90 days before and after receiving a diagnosis. Figure 6 presents the number of contacts or encounters six months before and after receiving a diagnosis.

5. Health care encounters 90 days before and after new diagnosis (N=63 patients)

	90 days before diagnosis		90 days after diagnosis	
	Range of # encounters		Range of # encounters	Trend
Phone	0-17	DIAGNOSIS	0-74	Increase
Email	0-19		0-33	Increase
Outpatient Visits	0-13		0-12	No change
ER Visits	0-1		0-1	No change
Hospital Visits	0-2		0-1	No change
All types	0-32		0-113	Increase

6. Health care encounters 6 months before and after new diagnosis (N=53)

	6 months before diagnosis		6 months after diagnosis	
	Range of # encounters		Range of # encounters	Trend
Phone	0-23	DIAGNOSIS	0-13	Decrease
Email	0-9		0-8	No change
Outpatient Visits	0-21		0-14	Decrease
ER Visits	0-1		0-1	No change
Hospital Visits	0-3		0-2	No change
All types	0-34		0-22	Decrease

Despite the limited number of cases, the data suggest that the number of encounters with clinic staff increased slightly at 90 days after diagnosis for the five patients who had received a diagnosis of Alzheimer's disease. The number of encounters overall decreased during the same interval for patients who had received a diagnosis of MCI. These figures may suggest that managed follow-up care was functioning according to established care coordination protocols for patients with a diagnosis of Alzheimer's disease. Further study with additional patient data could investigate whether and in what ways follow-up rates may be affected by diagnosis or other patient and family characteristics. Figure 7 presents these numbers.

7. Health care encounters before and after new diagnosis by diagnosis (N=63)

		90 days before diagnosis		90 days after diagnosis	
	N	**Range # encounters**	**DIAGNOSIS**	**Range # encounters**	**Trend**
Alzheimer's disease	5	0-9		3-16	Increase
Dementia	23	0-26		0-16	No change
MCI	33	0-32		0-113	Decrease
Other (unspecified)	2	0-0		0-4	Increase

Referral to support services

Based on a diagnosis of Alzheimer's disease, MCI, or related dementia, primary care providers recommended that patients and families consider additional services and supports provided by community partners. Care coordinators asked patients or families to sign a Release of Information form for the referral to one of four community partners.

Twenty-one patients or caregivers agreed to be referred for support services in the community, including 5 with a diagnosis of Alzheimer's disease, 9 with a diagnosis of dementia, and 7 with a diagnosis of MCI. Ten referrals were made to the Alzheimer's Association, 9 to the Senior LinkAge Line®, and 8 to Northwoods Partners by clinic staff, who contacted the organizations directly. Records do not indicate that any referrals were made directly to the Arrowhead Age Well program during the study period. Staff at the three community organizations contacted the patients or families to offer support and assistance, and followed up, as necessary, in order to reach the patients or families.

Services offered to patients and caregivers included a variety of supports through education, respite care, social activities, and a range of additional community referrals. Figure 8 presents the services that were recommended most often by agency staff, along with definitions of those supports and services.[11]

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[11] Definitions were provided by Senior LinkAge Line® and Alzheimer's Association partners.

8. Top supports and services recommendations received by patients and families (N=21)

Supports and services recommended by community partners	Number of times service was recommended
Caregiver support *(Referrals to services for the informal caregiver to reduce burden, increase confidence and ability to provide care)*	13
Communication *(Discussion of tips and strategies for communicating with person with dementia diagnosis)*	10
Community education/resources *(Referrals to non-medical supports available in the community, including community education, home care, adult day health, legal/financial resources, support groups, hospice, housing, Senior LinkAge Line®, chore services)*	10
Disease education *(Referrals to classes or presentations to help caregivers understand the basics of the disease, including stages, treatments, research opportunities, community support)*	9
Social activity *(Referrals to Memory Café, group respite, dementia-friendly senior center activities)*	7
Transportation *(Arrangements for volunteer or fee-for-service assistance in getting to appointments, activities)*	6
Early care consultation *(Assistance for caregivers of people in the early stage of the disease)*	5

The average number of services recommended was 4.5, with a range of 0 to 16 services. Agency staff reported back to Essentia staff about which services had been offered and which had been accepted. No information on the subsequent use of services by patients or caregivers was available for this report.

Cost of care

Essentia Health tracked direct and indirect costs[12] of care for clinic-based contacts associated with dementia for patients who had contacts or encounters with clinic staff between January 2014 and September 2015. Overall, average costs for Alzheimer's disease and dementia diagnoses and care appear to be higher and remain higher than those associated with MCI.

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[12] Charges are combined charges to patients and third party payers, and costs are combined direct and indirect costs to Essentia Health, for clinic based encounters associated with dementia.

The range in costs for diagnosis and care varied widely. Further analysis with individual level data linking specific individuals to costs and outcomes, could better reveal patterns or trends in service costs and patient outcomes.

Figures 9, 10, and 11 present the average and ranges of cost of diagnoses and care overall, and at 90 days and 6 months following diagnosis.

9. Combined direct and indirect costs* to Essentia Health for dementia diagnosis

Diagnosis**	N	Mean cost for diagnosis	Range of cost for diagnosis
Alzheimer's disease	5-6	$237	$93-$547
Dementia	21-23	$242	$0-$763
MCI	25-34	$199	$0-$879
Other (unspecified)	2	$102	$98-$106
Total	53-65	$215	$0-$879

** Figures have been rounded to the nearest whole dollar amount.*

*** Encounters with a HCPCS NeuroPsych testing code or an ICD-9 dementia code.*

10. Combined direct and indirect costs* to Essentia Health for dementia care at 90 days

Diagnosis**	N	Mean cost for care	Range of cost for care
Alzheimer's disease	5	$180	$0-$627
Dementia	23	$156	$0-$2160
MCI	32	$43	$0-$391
Other (unspecified)	2	$0	$0
Total	62	$94	$0-$2160

** Figures have been rounded to the nearest whole dollar amount.*

*** Encounters with a HCPCS NeuroPsych testing code or an ICD-9 dementia code.*

11. Combined direct and indirect costs* to Essentia Health for dementia care at 6 months

Diagnosis**	N	Mean cost for care	Range of cost for care
Alzheimer's disease	5	$391	$0-$1002
Dementia	21	$246	$0-$2315
MCI	25	$88	$0-$1726
Other (unspecified)	2	$59	$0-$118
Total	53	$178	$0-$2315

** Figures have been rounded to the nearest whole dollar amount.*

*** Encounters with a HCPCS NeuroPsych testing code or an ICD-9 dementia code.*

Key informant interviews

Interviews were completed with 21 staff and community partners in May and June, 2015. Interviews lasted from 20 minutes to one hour, depending on the amount of information that each key informant had to share with the interviewer. Wilder completed content analysis of interview data across key study questions, which include:

- Is there clear and shared agreement on the goals of the initiative and the intended outcomes for patients and families?
- How does the project work in a clinical setting and what are the steps to completing a screening and confirming the diagnosis?
- How are patients and families connected to additional supports and services? What services are used?
- What successes have been observed to date?
- What challenges have been observed to date?
- How might these results inform similar efforts in other communities?

Results

Is there clear and shared agreement on the goals of the initiative and the intended outcomes for patients and families?

Key informants were asked to describe the overall goal of the project, as well as the way in which they define success for the project. They indicated that there is clear and shared agreement. This was demonstrated by their creation of a system and set of tools that allowed medical staff to screen patients aged 65+, diagnose cognitive issues early, and connect patients and families with resources. A two part system allowed them to implement standardized best practice clinical protocols for early dementia screening and diagnosis, while collaborating with community partners and improving access to resources.

Representative comments from Essentia staff include the following:

> *The ultimate goal is early diagnosis, great services, helping them [patients] meet their personal goals and families goals, keeping them as healthy as possible.*
>
> *I think it's two-fold. One is screening and early diagnoses of early dementia, and second is giving options for patients and families who have that diagnosis.*

Representative comments from community partners include the following:

> *The goal was to connect Essentia patients, who have gone through testing, with community partners that could provide services and really bring the team together, kind of as a two way street. So, Essentia providing referrals and [my agency] being able to partner with them and create a continuum of care for their patients.*
>
> *The goal is to create a better referral system and diagnose patients earlier. It's also key to have a user-friendly hand-off system to connect patients with resources.*

How does the project work in a clinical setting?

Respondents described the process as including the following key components:

1. Screen all adults 65+ for cognitive impairment, using best practice screening tools
2. Change the medical culture and stigma of a dementia diagnosis, as there are effective non-medical treatment options that service to increase the quality of patient life
3. Utilize SmartSet EPIC (EMR) tools to guide work flow with patients
4. Key clinic staff oversee administration and guide daily program progress

One respondent explained the process in the following way:

> *…Once we have identified the patient as having an abnormal MiniCog, we are ordering further assessment, the MoCA©, the Montreal Cognitive Assessment. Then based on that, if they have an abnormal MoCA©, then we are getting them involved in Neuropsychology, if needed, and then, getting set up with community partners to work on things like exercise and socialization.*

How are patients and families connected to additional supports and services?

Respondents provided the following information about these connections:

- Direct referrals were made to community partners, through a Release of Information (ROI) provided by medical staff.
- Partners initiated immediate contact with patients and families after diagnosis to offer services and resources. They repeated attempts to make contact, as needed.
- Care is coordinated between community partners and referring clinic staff (RN Care Coordinator)
- Resources available to patients and families through community partners include dementia education and planning, exercise and socialization programming, caregiver services, respite, wellness programs, and home and community-based services such as chore/homemaker assistance, transportation and meals.

Community partners provided the following perspectives:

> *We connect people with mild/moderate cognitive impairments or any other form of dementia with non-medical services and supports, as well as state and federal programs that might help them. This also includes grants that may help them pay for services. We also connect family caregivers to support.*
>
> *We sit down with individuals and families after they have seen their primary doctor and taken their MoCA© exam, and then we provide education about the disease and behaviors. Then we create a care plan to help the individual know what to plan for and how to deal with changes in cognitive abilities. We also assist them in putting support systems in place…*

What successes have been observed to date?

Essentia staff and community partners believe that preliminary results are promising. They believe that the system flow is working as designed, and indicate the following key successes:

- Increased dementia screening of adults 65+
- Increased early diagnosis and community partner referral
- Increased communication and relationship building between Essentia Health staff and community partners that has led to high quality patient care and system implementation
- Patients are more likely to look into community resources sooner when it's recommended by a doctor they trust

Comments from Essentia staff that illustrate these points include the following:

> *I think we are getting more and more MiniCogs and MoCA©s done.*
>
> *I am seeing a standardized approach to what we are trying to achieve, and that is screening and intervening with patients earlier in the disease process.*
>
> *We are identifying folks with dementia earlier, so when I see more referrals for patients in early stage dementia, instead of moderate or late stage dementia, I think that is success.*
>
> *Having these folks [community partners] work with us is a big innovation. Utilizing their shared knowledge. The work flow we have established, having them right at the table, creating the model together with us and being shared care partners…Integrated health systems don't usually do that.*

Comments from community partners include the following:

> *We are defining success by seeing support systems and plans put into place. Keeping [patients] at home safely with a good quality of life is success.*
>
> *Instead of waiting for [the patient] to make contact, we make contact with [the patient]. So, that process of connecting the patient to the resource is almost immediate….The physician generally checks off a bunch of boxes of what he or she believes the patient needs….We know, based on that visit, what we should be suggesting and what we need to be offering. It streamlines the process.*
>
> *I think every time we're able to connect somebody to resources sooner because of this process, because of them being referred from a wellness visit…each one of those situations is an individual success.*

What challenges have been observed to date?

In spite of promising early successes, Essentia staff and community partners reported experiencing the following challenges:

- Time constraints on clinic nursing staff serving multiple roles have led to challenges with providing adequate Care Coordination Nursing Staff Resources.
- Convincing patients, families, and caregivers to plan for the future, take preventive action, and utilize available resources when cognitive impairment is still in the early stages.
- Connecting patients to resources on the same day they are diagnosed can be overwhelming and lead to information overload.
- Educating and training all clinic staff about the new protocols and how to utilize available resources.
- Communication and record-keeping challenges of community partners due to a lack of direct access to patient data gathered by Essentia.

Comments from Essentia staff that illustrate these points include the following:

> *The biggest challenge is what to do with these patients once we identify them because they do need a lot of support and resources, and that requires care coordination.*
>
> *The work flow and protocols have positively impacted our work, but it takes time to integrate it into our work.*
>
> *It feels like there isn't enough time or staffing to get done what needs to be done. And one thing in particular we found when dealing with these patients is that it takes a lot more time and energy, which is sometimes challenging for getting to the assessments and other work that needs to be done.*
>
> *Creating new work flows and then having them become "routine" is a challenge.*

Comments from community partners include the following:

> *We do not have the ability to enter the work we have done into patients' electronic medical records…It's important to keep the information updated so doctors can see the effects of community partner programs and services.*
>
> *A big challenge is just getting connected to the family…Depending on how soon they are called, they may not be ready.*
>
> *The biggest challenge is for [patients and families] to accept services. Some people might be in denial about what stage [of dementia] they are in.*
>
> *They just got a lot of information and then we are calling them…We try to get them to understand we are here to help, not make it more difficult.*

How might these results inform similar efforts in other communities?

Essentia staff have developed plans to expand implementation of the dementia protocols in three additional sites. Respondents noted the following important lessons that are guiding the expansion:

- Care Coordination nursing staff are essential to standardized implementation of the clinic protocols and coordination of the work flow system
- Having all stakeholders and staff involved in regular planning and coordination meetings helped to standardize implementation
- EMR technology resources are very useful for implementing new standard practices and for gradually introducing work flows and protocols to non-key staff members
- Using the Medicare Annual Wellness Visit is an effective contact point and incentive to bring in patients aged 65+ for screenings

Respondents explained these observations with the following comments:

> *Building relationships is key to the success of this initiative. Doctors', care coordination nurses', and community partners' teamwork and confidence in working with each other, referring patients and communicating well is key.*
>
> *With our use of electronic records, we designed a Smart Set… that's a way of having a very consistent work flow.*
>
> *The [procedures] are reproducible…They said they could take this project with that knowledge and reproduce it in their own clinic.*
>
> *The ability to replicate at other sites has gone well. We utilize the existing medical records, [and] we added features to try to design a system that would work within that [context].*

Family caregivers

In order to better understand the ways in which patients and families may benefit from integrated dementia capable protocols and community partner referrals for services and supports, Wilder Research completed qualitative interviews with two family caregivers, referred through one community partner.

Semi-structured phone interviews lasted about an hour and covered the following topics:

- Patients' and families' experiences with screening, receiving results, and follow-up diagnostics
- Their experiences with receiving referrals to and services from community partners, including barriers and likelihood of recommending the agency to others

Results are presented in narrative form, with identifying information omitted or changed.

Results

Family #1. An adult is the primary caregiver for the spouse, who received a diagnosis of Alzheimer's disease.

When the spouse first received the official diagnosis, the caregiver was unhappy with the approach, which seemed clinical and quick. The primary care physician provided some helpful clarification, and they have experimented with a variety of prescribed medications since then.

The caregiver was referred to the community partner, but delayed contact, believing that they had no need for support at that time. Eventually, the caregiver visited the community partner in person to find out what might be available, and received a packet of information about Alzheimer's disease and other resources. The caregiver had already accumulated a significant amount of information and did not see that the packet provided new resources. Since that time, the caregiver had made use of transportation services, and now participates in a support group that the caregiver believes is very helpful. The following quotation illustrates this point:

> *You can feel all alone in your situation, and then you find out that you are not. People talk about their experiences and how they have dealt with them, which is helpful.*

According to the caregiver, the community partner provides ongoing information and resources, and has also suggested respite care and home health services for bathing. The caregiver reported that they do not believe these services are necessary at this time. The caregiver also said that they have not experienced any barriers to receiving services.

The caregiver would consider contacting the partner for additional assistance, and offered high praise for the support received from the community partner:

> *I know [the partner], not as a personal friend, but well enough to say "Hi. How are you?" and that sort of thing. And she feels free to get on the phone and call me if she thinks there is something going on, or she has some information that maybe would help me. She communicates with me frequently."*

Family #2. An adult helps care for a sibling, who received a diagnosis of dementia.

The caregiver was not involved in the appointments for initial testing and follow-up, but reported that the sibling feels very positive about the interactions with the care coordinator from Essentia. While the sibling with dementia gave permission to be contacted by the community partner about available services, the caregiver did not know the outcome of any follow-up.

Concerns on the part of the caregiver about the sibling's isolation, led the caregiver to contact the community partner agency for additional assistance. Staff from the agency completed a home visit and suggested a range of services, including grocery shopping, transportation, support group, friendly visiting, and home exercise. Complex family dynamics have been a barrier to following through and providing these services for the sibling.

The caregiver called the community partner a "top-notch organization," and would not hesitate to contact the agency for additional assistance. The following comment illustrates the caregiver's perspective:

> *[The agency] has done an excellent job communicating with me. I am very impressed by the level of discretion and professionalism exhibited by [the agency]. I am aware of the difficult position they face in this [complex family] situation.*

The caregiver went on to say:

> *I am grateful for the support we have received from [the agency] and the Essentia care coordinator. It has been essential to my well-being as a caregiver.*

Limited access to patients served through this initiative makes it difficult to draw conclusions about the overall success of the project from the vantage point of patients and families. However, the two cases help to illustrate the potential benefit that can be gained by referral to community resources. Further follow-up would be necessary to identify useful strategies for engaging patients and families and likely benefits associated with the use of community resources.

Summary conclusions and issues to consider

Background

Essentia Health received a Community Service/Services Development grant (now Live Well) from the MN Department of Human Services to explore new strategies for standardizing diagnosis and follow-up care for dementia, and to increase the potential use of community resources and supports. By integrating and centralizing care in the primary care function, Essentia Health expected to:

- Improve early access to clinical and community support for patients and families
- Address practical, social, and emotional needs for patients and families with information and resources

The evaluation completed analysis of aggregated data for patients who received screening and follow-up care; and assessed feedback from interviews with 21 Essentia staff and community partners involved in the planning and implementation of program strategies, and from interviews with two family caregivers.

Conclusions

Program results and outcomes suggest that the grant project has achieved the following key objectives:

- Developed and implemented work flow protocols to guide work with adults aged 65 and older
- Successfully integrated the new dementia protocols in clinics in West Duluth and Ely
- Screened older adults during routine wellness visits
- Completed additional diagnostic testing in a timely manner
- Engaged patients and families in care coordination efforts
- Referred patients to community partners for additional services and supports

The evaluation cannot draw conclusions about the extent to which patients and families made use of community-based supports, nor can it determine the extent to which patients and families benefited from the supports available. Nonetheless, anecdotal information from the two families available for follow-up suggests that the connection to community services can be valuable for those who choose to avail themselves of these resources.

Issues to consider

This report, although somewhat limited in scope, indicates that there can be significant value in revamping clinic protocols to conduct more uniform screening of older adults who present with potential cognitive issues. The evaluation demonstrates that clinic staff were engaged and felt positive about this change in approach, despite some concerns about the added burden associated with the work required by the protocol. They were also grateful to know more about the community resources available, connect families to these resources, and have community-based partners available to support patients and families at home.

There are several aspects of this work, however, that could likely benefit from further consideration, including the following:

- Of the 66 patients who received a dementia-related diagnosis, 45 (68%) declined an offer for referral. This may be related to many factors, including the timing of the request for a release of information, the approach used in making the request (would a warm hand-off a few days after the diagnosis been more effective?), the patients' or family members' perceived needs at the time, the patients' or families' understanding of what signing a release would mean, and other family-based factors that would be unknown to clinic staff. Further study is needed to better determine the best timing and techniques for helping families to consider the potential value of outside resources. Potential recommendations to consider include:
    - Have community partners available at the clinic site on a limited basis to meet with families.
    - Engage other clinic staff, perhaps those who are not direct patient care workers, to engage with family caregivers in discussing what care needs might be anticipated at home and how those needs can be addressed.
- To better understand the service costs associated with a dementia-related diagnosis and potential strategies for reducing those costs it would be necessary to conduct an analysis of individual case level data, which was not available for this report. The wide variation in costs, based on the data provided by Essentia, suggests that there would be value in learning more about where and how these costs are incurred and in which cases there may be an opportunity to reduce costs through a change of procedure or approach. One potential recommendation to consider includes:

  - Conduct a case review of the most and least expensive cases, review commonalities and differences among these cases, and formulate a cost reduction plan based on these analyses.

- Clinic staff reported some added burden and time requirements associated with the change in the dementia service protocol initiated as part of this project. This may represent a barrier to broader implementation, given the current plan to expand to other clinics. One potential recommendation to consider:

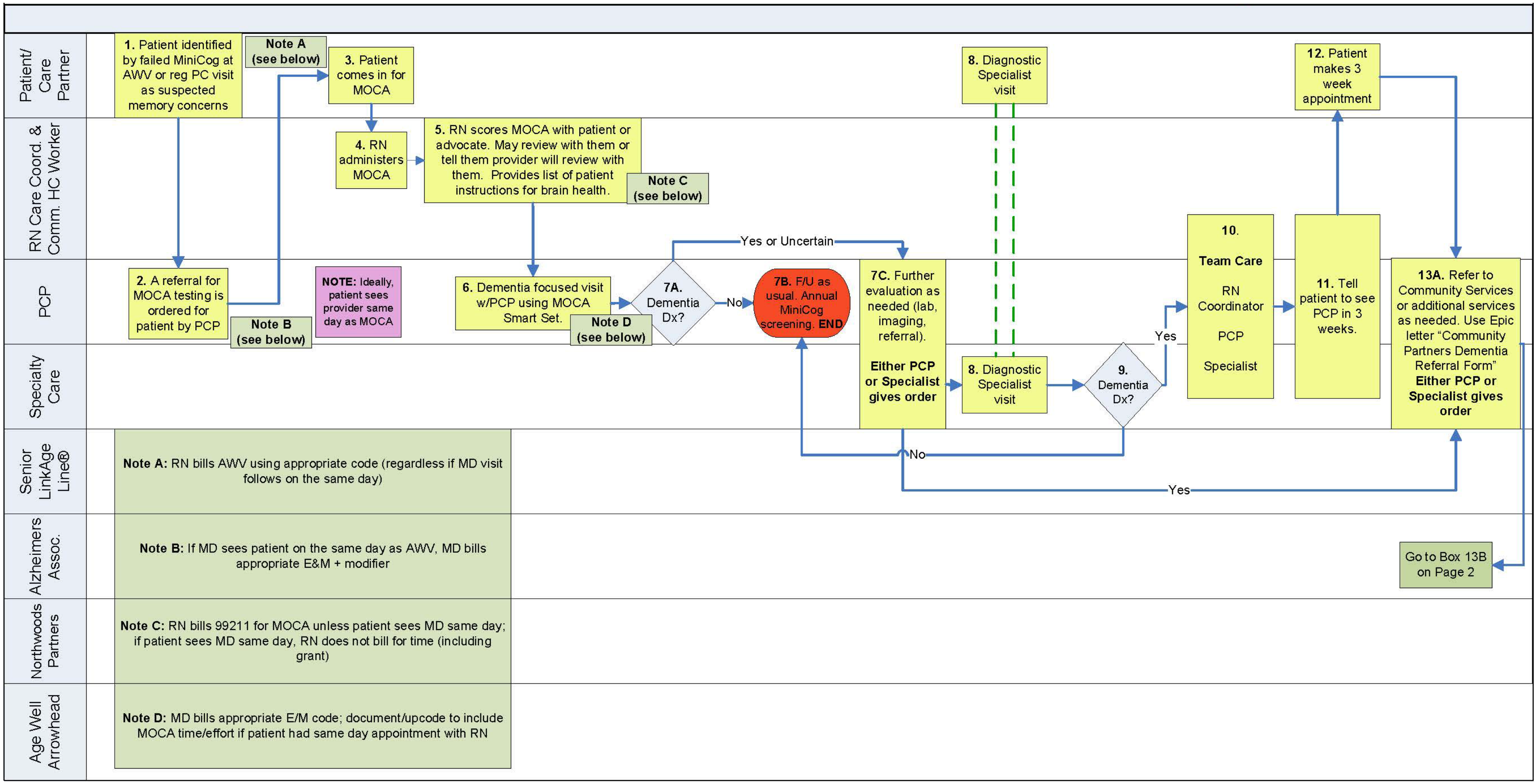
  - Conduct a focus group with clinic staff at existing program sites prior to expansion to other clinics to find out how this added burden is experienced, how and when it occurs, what clinic staff have done to mitigate this burden, and to brainstorm other strategies that clinic staff might consider to address this issue. This could also be an opportunity for clinic staff to consider how to improve engagement and uptake of community-based services.

- The impact and benefits associated with an enriched dementia care model cannot be fully demonstrated in this evaluation. To more adequately demonstrate project benefits would require a patient follow-up evaluation that not only includes follow-up with those families who opt for community-based services, but also with those who opt not to use recommended services. One recommendation to consider:

  - Develop a study that focuses exclusively on how referral to community-based supports impacts families, including questions about reasons for opting in or out, a discussion of the family perceptions of how the recommendation for a referral occurred in the clinic setting, care situations and family contexts that may trigger an openness to outside supports, and an examination of the types of supports families have found most useful.

Appendix

Work Flow Process Map (on 3 pages)



Note A: RN bills AWV using appropriate code (regardless if MD visit follows on the same day)

Note B: If MD sees patient on the same day as AWV, MD bills appropriate E&M + modifier

Note C: RN bills 99211 for MOCA unless patient sees MD same day; if patient sees MD same day, RN does not bill for time (including grant)

Note D: MD bills appropriate E/M code; document/upcode to include MOCA time/effort if patient had same day appointment with RN

DATE	DESCRIPTION	DEVELOPED BY
7/22/2014	DEMENTIA GRANT WORK FLOW	DEMENTIA GRANT TEAM (DRAWN BY NANCY TARIO, PROCESS EXCELLENCE DEPT)

FULL FILENAME
Z:\PROCESS EXCELLENCE\PROCESS EXCELLENCE\PROJECTS\FY14\TARIO, NANCY - DEMENTIA GRANT\PROCESS FLOW - REVISED 12-12-14.VSD

REVISIONS

REV BY	DESCRIPTION	DATE REV	APPROVED

Key:
Dashed line means communication may go both ways

PAGE
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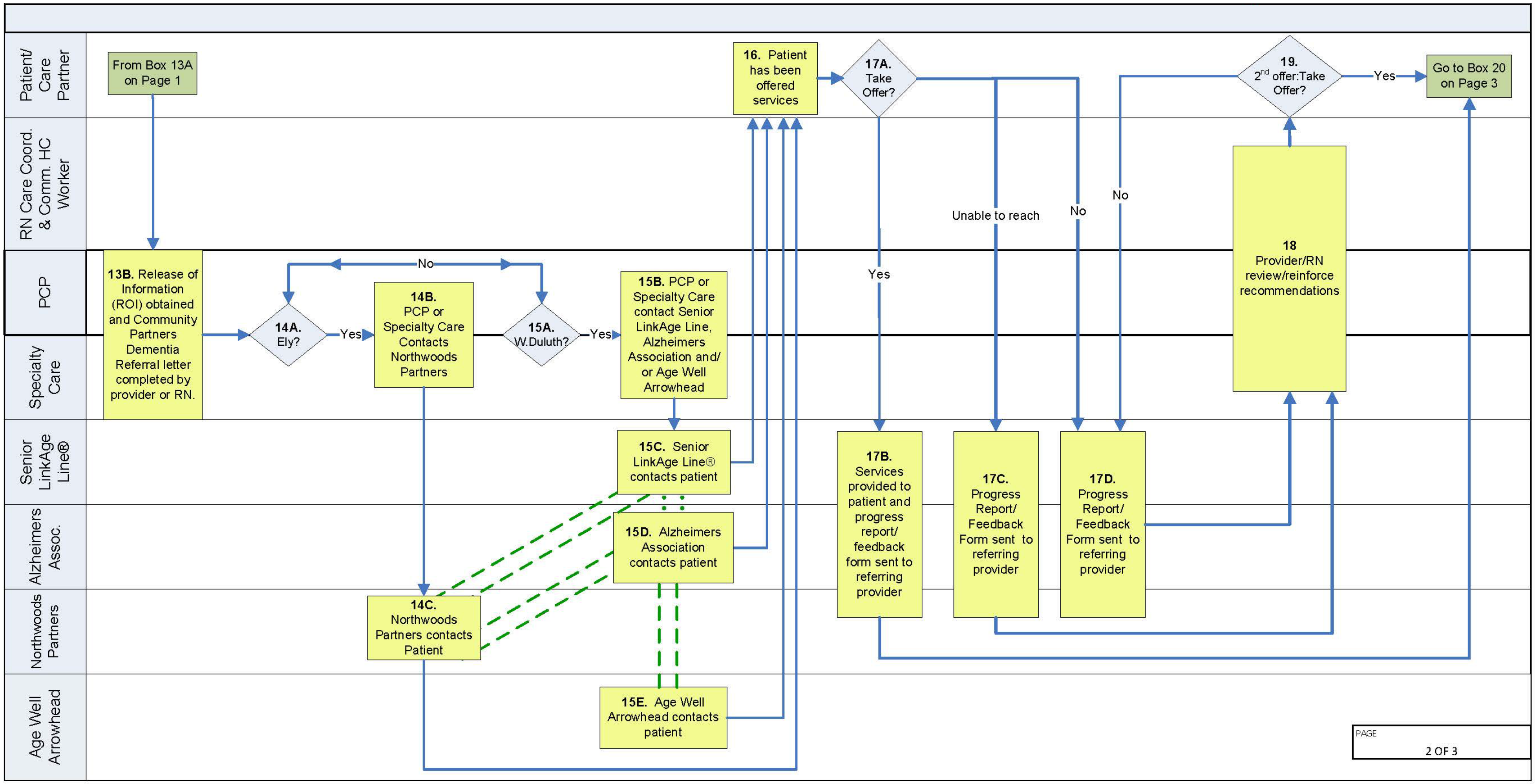
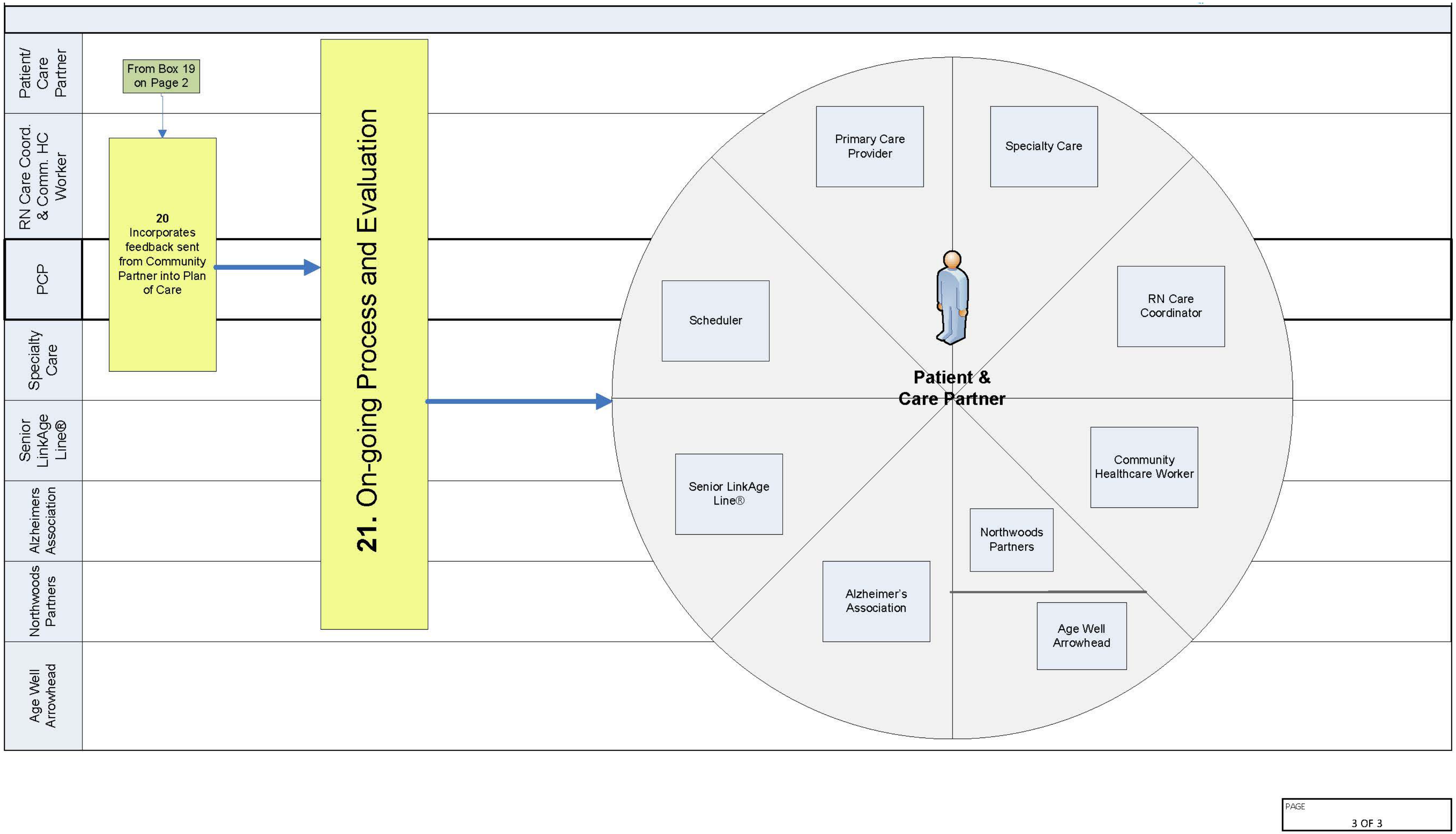


Key:
Dashed line means communication may go both ways


Patient/ Care Partner
RN Care Coord. & Comm. HC Worker
PCP
Specialty Care
Senior LinkAge Line®
Alzheimers Association
Northwoods Partners
Age Well Arrowhead
From Box 19 on Page 2
20 Incorporates feedback sent from Community Partner into Plan of Care
21. On-going Process and Evaluation
Primary Care Provider
Specialty Care
RN Care Coordinator
Community Healthcare Worker
Northwoods Partners
Age Well Arrowhead
Alzheimer's Association
Senior LinkAge Line®
Scheduler
Patient & Care Partner
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